No. 98. An act relating to the Rare Disease Advisory Council.

(H.46)

It is hereby enacted by the General Assembly of the State of Vermont:

Sec. 1. FINDINGS

The General Assembly finds that:

(1) lack of awareness contributes to common and harmful obstacles that rare disease patients face, such as delays in diagnosis, misdiagnosis, lack of treatment options, high out-of-pocket costs, and limited access to medical specialists; and

(2) with the support of the National Organization for Rare Disorders, various patient organizations, and stakeholders in the rare disease community, rare disease advisory councils are enabling states to strategically identify and address barriers that prevent individuals living with rare disease from accessing adequate and effective treatment and care for their condition.

Sec. 2. 18 V.S.A. chapter 19 is added to read:

CHAPTER 19. RARE DISEASES

§ 981. RARE DISEASE ADVISORY COUNCIL

(a) Creation. There is created the Rare Disease Advisory Council within the Department of Health to provide guidance and recommendations to the public, General Assembly, and other government agencies and departments, as necessary, regarding the needs of individuals living with rare diseases in Vermont.

(b) Membership.

(1) The Advisory Council shall be composed of the following members:

(A) two individuals living with a rare disease, at least one of whom is an older Vermonter, appointed by the Commissioner of Health;

(B) a parent or guardian of a person living with a rare disease, appointed by the Commissioner of Health;

(C) the Commissioner of Health or designee;

(D) the Commissioner of Disabilities, Aging, and Independent Living or designee;

(E) a representative of the Health Equity Advisory Commission established pursuant to section 252 of this title;

(F) an academic researcher who conducts rare disease research, appointed by the Commissioner of Health;

(G) a physician practicing in Vermont with experience treating a rare disease, appointed by the Vermont Medical Society;

(H) a nurse practicing in Vermont with experience treating a rare disease, appointed by the Vermont chapter of the American Nurses Association;

(I) a pharmacist practicing in Vermont, appointed by the Vermont Pharmacists Association;

(J) a geneticist or genetic counselor, appointed by the Commissioner of Health; and

(K) any other persons deemed necessary by the Commissioner of Health.

(2) Members of the Advisory Council shall be appointed for staggered five-year terms. Any midterm vacancy shall be filled by the appointing authority for the remainder of the unexpired term. Terms shall begin on January 1 of the year of appointment and conclude on December 31 of the last year of the member's term. Members of the Advisory Council may serve multiple terms, either consecutively or intermittently.

(3) The Advisory Council may collaborate with any other relevant stakeholders it deems appropriate, including the National Organization for Rare Disorders.

(c) Powers and duties. The Advisory Council may conduct the following activities for the benefit of individuals impacted by rare diseases in Vermont:

(1) convene public hearings and solicit comments from individuals impacted by rare diseases to assist the Advisory Council with creating a needs assessment identifying gaps in services for individuals with a rare disease in Vermont and the needs of their caregivers and providers;

(2) provide testimony and comments on pending legislation and rules that impact Vermont's rare disease community before the General Assembly and other State agencies;

(3) in consultation with experts on rare diseases, develop and provide policy recommendations that:

(A) identify conditions for the Department of Health to consider as part of appropriate screening guidance and recommendations; and

(B) support timely patient access to diagnostic services and treatment and enhance quality of services provided by rare disease specialists; and

(4) any other activities identified by a majority of the Advisory Council.

(d) Assistance. The Advisory Council shall have the administrative, technical, and legal assistance of the Department of Health. The Department shall maintain a web page on its website that contains notices of upcoming meetings, meeting minutes, public comments, and reports.

(e) Report. As needed, the Advisory Council may submit any recommendations for legislative action to the House Committees on Health Care and on Human Services and to the Senate Committee on Health and Welfare.

(f) Meetings.

(1) The Commissioner of Health or designee shall call the first meeting of the Advisory Council.

(2) Annually, the Advisory Council shall elect a member to serve as the Chair.

(3) The Advisory Council shall meet quarterly. Meetings may be held in person or remotely on an electronic platform in accordance with the Vermont Open Meeting Law set forth in 1 V.S.A. §§ 310–314.

(4) A majority of the membership shall constitute a quorum.

(g) Compensation and reimbursement. The members of the Advisory Council not otherwise compensated for their participation shall be entitled to per diem compensation and reimbursement of expenses as permitted under 32 V.S.A. § 1010 for not more than four meetings annually.

Sec. 3. LONG COVID RESOURCES FOR PRIMARY CARE PROVIDERS AND PATIENTS

(a) On or before January 1, 2027, the Department of Health shall collaborate with the University of Vermont Medical Center, the Vermont Medical Society, and patients with lived experience of long COVID to:

(1) identify existing evidence-informed standards, best practices, and training for primary care providers regarding long COVID and distribute these resources through the Department's website and to primary care providers; and

(2) in collaboration with the Department of Disabilities, Aging, and Independent Living, identify support services or other resources for long COVID that include a range of peer and community-based programs, such as long COVID support groups through the University of Vermont Medical Center, the Vermont Center for Independent Living, or another entity, and strategies to support patients who are homebound or at risk of becoming homebound.

(b) On or before February 1, 2027, the Department of Health, in collaboration with the Department of Disabilities, Aging, and Independent Living, shall present recommendations to the House Committee on Human

Services and the Senate Committee on Health and Welfare on providing long-term disability supports to individuals experiencing long COVID.

(c) As used in this section, “long COVID” means postacute sequelae of SARS-CoV-2 infection.

Sec. 4. EFFECTIVE DATE

This act shall take effect on July 1, 2026.

Date Governor signed bill: May 18, 2026